

CHAPTER 1. INTRODUCTION

1.1. Office for Children with Special Health Care Needs (OCSHCN)

The Office for Children with Special Health Care Needs (OCSHCN) within the Arizona Department of Health Services was formed in 1993. Since its inception, OCSHCN has operated on the principle that the family is the center of the health care experience, the most important participant in the system of care for children with special health care needs. This philosophy, along with a belief that services are enhanced in a system that is accountable, cost effective and responsive to multiple stakeholders, is embedded in the Vision, Mission and Guiding Principles defined in OCSHCN's Strategic Plan.

The OCSHCN operates under the authority of A.R.S. 36-132 for the Arizona Department of Health Services (ADHS), A.R.S. 36-261 for Children's Rehabilitative Services, Title V of the Social Security Act for Maternal and Child Health Services and Intergovernmental Agreements with the Arizona Department of Education (ADE), Economic Security (ADES) and the Arizona Health Care Cost Containment System (AHCCCS).

The work that is done through OCSHCN programs, and the advocacy and educational efforts of community partnerships, will assist in meeting one or more of the following Maternal and Child Health Bureau Title V National Performance Measures as they apply to Children and Youth with Special Health Care Needs (CYSHCN) (available at <http://www.mchb.hrsa.gov/grants/proposed.htm>): the percent of screen positive newborns who receive appropriate follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs; the percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive; the percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home; the percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need; percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily; and the percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

OCSHCN is organized around five functional areas that were defined as part of the strategic planning process: Data, Planning and Evaluation, Systems of Care Development, Education, Advocacy and Member Rights, Finance and Business Operations and Children's Rehabilitative Services.

1.2. Vision

All children and youth with special health care needs have the opportunity to reach their full potential.

1.3. Mission

The mission of the Office for Children with Special Health Care Needs is:

To continuously improve comprehensive systems of care that enhances the health, future and quality of life for children and youth with special health care needs, their families and the communities in which they live.

1.4. Target Population

The target population for the Office for Children with Special Health Care Needs is: Children and youth age birth to 21 with special health care needs, their families and the communities in which the children, youth, and families live. Children and youth with special health care needs are individuals who have or are at risk for chronic (can be expected to last more than a year) physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children and youth generally. Children and youth with special health care needs may require:

- A. prolonged or periodic hospitalizations that are longer than the average stay or with greater frequency than the general population;
- B. adaptations for daily living due to health related functional limitations; and/or
- C. a special level of expertise for treatment and/or services from multiple disciplines.

1.5. Guiding Principles

The Guiding Principles are all of equal importance and apply to the work throughout the Office for Children with Special Health Care Needs. The policy, practice, administrative and programmatic initiatives will reflect adherence to the Principles. The Office for Children with Special Health Care Needs believes that every child and youth with special health care needs can, through care and development, grow with the confidence and self-esteem to reach their full potential and be recognized as a contributing member of their community. Additionally, attention to capacity building activities is included throughout the work of OCSHCN. With that overriding belief, the system of care will be developed consistent with the following guiding principles:

Principle 1: Informed Decision Making. When children, youth and families are fully informed and understand the options available, better decisions can be made regarding individual treatment and services. When key stakeholders such as the children, families, public policy makers, community leaders, and program personnel are fully informed and empowered, decisions lead to more effective systems of care.

Principle 2: Easy Access to Care and Services. Promoting early diagnosis and treatment and timely, ongoing, and readily available care leads to optimal use of resources and more children and families receiving the most appropriate services.

Principle 3: Parent and Child Involvement. Establish meaningful involvement of children, youth, and their families in all aspects of care and in the development, planning, implementation, and evaluation of programs and policies of the system of care.

Principle 4: State of the Art Medical Care and Support Services. Through research, education, training, and evaluation, children, youth, and families are provided a choice of state-of-the-art medical and support services, which can lead to the best outcomes and highest quality of life.

Principle 5: Accountability. A system of care, which is accountable to the child, youth, and family as primary stakeholders, along with communities, providers of service, and other stakeholders leads to the highest quality of care through communication, monitoring and publishing measurable outcomes, performance standards, and cost data.

Principle 6: Diversity. Service delivery which is respectful of the lifestyle, environment and strengths of the individual and family, their ethnic and cultural perspectives and their economic condition provides a system that is responsive to the individual needs as well as community abilities.

Principle 7: Partnerships and Collaboration. Effective policy and service delivery systems are best developed through action, learning, relationship development and building on the strengths of the existing systems and communities. Partnerships and collaborations within the

Department of Health Services and external to the Department will be defined in all our work with agencies, communities, providers and other systems of care.

Principle 8: Family Centered System of Care. Children, youth and their families are more able to meet their needs when they are supported within a system of care built on parent and professional partnerships, cultural competency and community based approaches.

Principle 9: Marketing and Information Sharing. Providing leadership in raising the awareness of children, families, community members, providers, public policy decision makers and the general public about the needs and strengths of children with special health care needs and the system of care results in better outcomes and responsive systems of care and communities.

Principle 10: Comprehensive Approach to Service Delivery. Children, youth, and families have the ability to reach their full potential when they have access to a comprehensive array of services and supports designed to meet the individual special needs of the child, youth, and their family in the context of their community and their natural environment.

Principle 11: Enhanced System of Care. The coordination and integration of OCSHCN services and supports with other service delivery systems will result in the most effective, comprehensive system of care for children and families. Partnerships driven OCSHCN initiatives, which lead to system-wide improvements, have the greatest potential for improving outcomes for children, youth, and their families.

Principle 12: Cost Effective. Service delivery and system of care development will be based on providing the most quality, cost effective and efficient services that provide the greatest benefit for the largest number of children, youth, and families served.

1.6. Overview of the Family Resource Coordination Program

ADHS/OCSHCN provides Family Resource Coordination for members who have certain medical and/or behavioral conditions, traumatic brain injury, spinal cord injury, or other special health care needs.

OCSHCN contracts with agencies throughout the state to provide Family Resource Coordination in each of the 15 counties in Arizona through a comprehensive, coordinated, interagency, multi-disciplinary, and family centered approach. Through the development of the Individual Service Plan (ISP), families identify needs, priorities, concerns, resources and desired outcomes as well as federal, state, and community resources for which they may be eligible.

A member's health and development are enhanced and complications ameliorated or eliminated as a result of Family Resource Coordination. Educational costs may be reduced with a decreased need for special education and related services. Families are assisted in meeting their unique needs, thus relying less on assistance from others. Federal, state, local, and private resources are better coordinated to eliminate duplication or gaps in service.

Family Resource Coordination ensures that the service delivery system is accessible for each enrolled member and family. Family Resource Coordinators are responsible for securing and coordinating services across agency lines, and serve as an initial point of contact in helping children, youth, and families obtain services and assistance.

- A. What the Family Resource Coordination Program and a Family Resource Coordinator Can Do
- Listen / be supportive.
 - Be respectful of beliefs, ideas and culture
 - Provide information and/or educational materials
 - Assist the member and/or the family to:
 - Determine priorities

- Assess resources and needs
 - Identify other/additional resources
 - Navigate the multiple service delivery systems
 - Assist completing forms and applications for services
 - Identify service providers
 - Coordinate services
 - Assist with meeting transportation needs
 - Identify potential funding sources
 - Assist members and families to reach an optimum level of wellness, functional capability, and autonomy, and support activities that will empower them to act as their own advocate
- B. What the Family Resource Coordination Program and a Family Resource Coordinator Cannot Do
- Evaluate, counsel, or advise
 - Provide therapeutic services
 - Provide mental health services
 - Serve as “ first responder” or emergency service provider
 - Develop an Individual Education Plan (IEP) or actively participate in an IEP team meeting because:
 - Family Resource Coordinators are not educational or IDEA experts

1.7. Goals

The goal of ADHS/OCSHCN Family Resource Coordination is to assist families of members with special health care needs. Appropriate services and/or benefits are identified and coordinated through the development of an Individual Service Plan (ISP) and the facilitation of positive working relationships with the member, family, and other service providers.

A. Objectives

1. Provide culturally appropriate, consistent, family-centered services, which encourages collaboration and partnership among members/families, policy-makers, and health care providers. Provide family centered practices that include:
2. Honoring family diversity and values by:
 - Learning who the family members are, and who wants/needs to be involved
 - Helping families identify and use their preferred support networks
 - Performing all efforts necessary to assure the physical, developmental, emotional, social, educational, and cultural needs of each member and his/her family is reflected in the planning and delivery of care
 - Honoring the family’ s religion, values, customs or preferences regarding language, health practices, kinship, food, and holidays
 - Learning what support the family wants. Allowing families to choose their preferred spiritual resources, including staff that shares the language and ethnicity of the member/family
 - Providing educational materials and services in the languages of the family and surrounding community
3. Building family relationships through:
 - Showing respect for the member by accepting the whole person, with his/her strengths and vulnerabilities
 - Making getting to know members/families a priority

- Indicating sensitivity through understanding that the member influences and is influenced by his or her environment
- Supporting a member's growth and change
- Rooting relationships in goal identification by the member with support and assistance in obtaining resources from the agency
- Learning what support the family wants
- Utilizing mutually agreed upon channels of communication consistently
- Having frequent discussions on how the collaborative relationship with the member is evolving
- Delivering quality services by setting standards based upon values and ethics
- Recognizing that families set standards for themselves based upon values and personal ethics
- 4. Building collaborative relationships based upon the following concepts:
 - Providers and members/families involved in building collaborative relationships need and deserve the support of supervisors and organizations
 - All learning takes place in the context of relationships and is critically affected by the quality of those relationships
 - Relationships are the medium. How one is in a situation has an important effect on what gets done
 - Everyone brings to a situation their past experiences, values, and expectations.
 - Everyone is, likewise, responded to in terms of other people's experiences, values, and expectations
 - The golden rule of building collaborative relationships: "Do unto others as you would have others do unto others"
- 5. Provide resource services including assisting families in understanding and accessing medical organizational systems, the education system, and community and public resources, so they can work more easily with families
- 6. Communicate information to the family in their primary language and in writing when practical
- 7. Work in partnership with members, families, and other team members utilizing a relationship-based approach to develop and implement the Individual Service Plan (ISP).
- 8. Assist families in acquiring the knowledge and skills they need to support the development of their child who has special needs and become more effective advocates
- 9. Support families to locate, communicate with, secure, and coordinate services among all providers, including health professionals, emphasizing a team approach
- 10. Assist families to identify and access resources and natural supports within their family, neighborhood, and community

B. Roles and Responsibilities

ADHS has designated OCSHCN as responsible and accountable for the TBI/SCI/CYSHCN Family Resource Coordination Program goals and expenditures. The ADHS/ OCSHCN TBI/SCI/CYSHCN Family Resource Coordination Program performs a variety of roles in the oversight of services such as: partner, monitor, facilitator, technical advisor, and payer.

1. TBI/SCI/CYSHCN and its contractors share a dynamic role in the development and evolution of the Family Resource Coordination Program.
2. TBI/SCI/CYSHCN contracts with local public and private agencies (Contractors), which recruit, manage, and network with a unique group of specialized providers.

3. TBI/SCI/CYSHCN provides the criteria, policies, procedures and other requirements for developing and implementing high quality, appropriate services.
4. Contractors are expected to utilize methods that are appropriate for the demographics and particular characteristics of their community and to determine how to achieve program standards and identified outcomes.
5. The Guiding Principles apply to the work throughout TBI/SCI/CYSHCN and support the family-centered approach that is the cornerstone of this program.

1.8. Use and Revision of Policies and the Manual

The purpose of the manual is to document the TBI/SCI/CYSHCN Family Resource Coordination Program Policy Standards for implementation and management of the program. The manual is to be used as a reference and information resource for Contractors, TBI/SCI/CYSHCN Administration, and other interested parties in fulfilling the mission of the program. The Policy Standards contained in the manual are the minimum acceptable requirements to contract with TBI/SCI/CYSHCN for the provision of services.

Policy Standards are the foundation for the TBI/SCI/CYSHCN Program. Policies have been developed by interpreting legislation and legal requirements, understanding member needs, evaluating existing implementations, and by considering the cultural environment. The TBI/SCI/CYSHCN Program is constantly changing. Policy Standards will be revised as required to comply with changes in law or administrative rules or to enhance program effectiveness. The ADHS/OCSHCN TBI/SCI/CYSHCN Family Resource Coordination Program Manager owns the Policy Standards.

Updates or changes to TBI/SCI/CYSHCN Family Resource Coordination Policy Standards, which include establishing new policy standards, modifying existing policy standards, or removing policy standards, can only be made by the ADHS/OCSHCN TBI/SCI/CYSHCN Family Resource Coordination Program Manager and can result from two different processes:

- A. Annual review corresponding with the end of a contract or legislative session. The ADHS/OCSHCN TBI/SCI/CYSHCN Family Resource Coordination Program Manager, or designate, will review the Policy Standards for possible addition, revision, or deletion. An addition, revision or deletion is created if it is deemed appropriate.
- B. Any User may propose the establishment, revision, or deletion of any policy principle at any time. These proposals should be directed to the ADHS/OCSHCN TBI/SCI/CYSHCN Family Resource Coordination Program Manager who will evaluate and accept or deny the proposal.

Revisions to policies and the manual will be distributed to all Contractors at least 30 days prior to the effective date of any change, when appropriate. Contractors shall adhere to the requirements and guidelines set forth in the manual and are also responsible for incorporating any policy changes into their operation.

The manual will be reviewed at least annually and revised as necessary. If the manual does not answer questions and concerns or if there are suggestions for changes to the manual, to clarify a policy, to update a procedure, or to suggest additional information to be included in the policy manual, recommendations or suggestions may be sent in writing or by fax to the ADHS/OCSHCN TBI/SCI/CYSHCN Family Resource Coordination Program Manager. Recommendations and suggestions will be considered during the review process.